

Exhibit A

Submission Date	Decision Date	Accept/Reject	Disorder	Brief Description	Neuro/Chrom	Intellectual Deficits	Adaptive Deficits	Information Source(s)	Reason to Reject	Committee Lead
8/5/2010	11/6/2010	Reject	1.5 megabase deletion on chromosome 1q23.1 to q22	None found	Chromosomal	Unknown	Unknown	http://ghr.nlm.nih.gov/search?query=1.5+megabase+deletion+on+chromosome+1q23.1+to+q22&Search=Search	Base on the OCDC criteria adopted 10/13/10 this submission has been rejected as a "condition similar to mental retardation" because the name of the condition returns no results in our research.	linda lunsford
9/14/2010	11/6/2010	Reject	19Q Duplication	None found	Chromosomal	Unknown	Unknown	http://ghr.nlm.nih.gov/search?query=19q+duplication&Search=Search	Base on the OCDC criteria adopted 10/13/10 this submission has been rejected as a "condition similar to mental retardation" because the name of the condition returns no results in our research.	linda lunsford
7/29/2010	8/12/2010	Accept	3p25 deletion syndrome	3p deletion syndrome is a rare contiguous-gene disorder involving the loss of the telomeric portion of the short arm of chromosome 3 and characterized by developmental delay, growth retardation, and dysmorphic features.	Chromosomal	Yes	Yes			linda lunsford
5/25/2011	10/19/2011	Reject	Agenesis of Corpus Callosum	A rare disorder characterized by a partial or complete absence of an area of the brain that connects the two cerebral hemispheres.	neurological	No	No	http://www.ninds.nih.gov/disorders/agenesis/agenesis.htm	Prognosis depends on the extent and severity of malformations. ACC does not cause death in the majority of children. Mental retardation does not worsen. Although many children with the disorder have average intelligence and lead normal lives, neuropsychological testing reveals subtle differences in higher cortical function compared to individuals of the same age and education without ACC	
8/5/2010	8/30/2010	Accept	Agyria (Lissencephaly)	Lissencephaly, which literally means "smooth brain," is a rare, gene-linked brain malformation characterized by the absence of normal convolutions (folds) in the cerebral cortex and an abnormally small head (microcephaly).	Chromosomal	Yes	Yes			linda lunsford
6/10/2010			Aicardi Syndrome							
8/4/2010	8/17/2010	Reject	Alcohol Related Neurodevelopmental Disorder (ARND)		neurological	No	No	Details to come		
3/16/2010	6/8/2010	Accept	Angelman Syndrome	Also called "Happy Puppet Syndrome"; results in intellectual disability, severe speech impairment, problems with movement, and recurrent seizures	Genetic disorder that primarily affects the nervous system	Yes	Yes	Genetics Home Reference: http://ghr.nlm.nih.gov/condition=angelmansyndrome		Linda Lunsford
7/8/2010	8/10/2010	Reject	Apert's Syndrome	Apert syndrome is a genetic disorder characterized by the premature fusion of certain skull bones (craniosynostosis).	Chromosomal	No	No	http://ghr.nlm.nih.gov/condition/apert-syndrome	cognitive impairment is not characteristic	

7/5/2010	8/2/2010	Reject	Ataxia (Spinocerebellar)	progressive disorder affecting the nervous system	neurological	No	No	http://ghr.nlm.nih.gov/condition/infantile-onset-spinocerebellar-ataxia	primarily a physical condition not affecting cognitive functioning	Linda Lunsford
9/7/2010			Bardet-Biedl Syndrome							
	11/15/2010	Reject	CHARGE Syndrome	CHARGE stands for coloboma, heart defect, atresia choanae (also known as choanal atresia), retarded growth and development, genital abnormality, and ear abnormality.	unknown	No	No	http://ghr.nlm.nih.gov/condition/charge-syndrome	Individuals have a wide range of cognitive function, from normal intelligence to major learning disabilities with absent speech and poor communication.	
6/23/2010	6/30/2010	Reject	Chiari Malformation	Chiari malformations (CMs) are structural defects in the cerebellum, the part of the brain that controls balance.	neurological	No	No	http://www.ninds.nih.gov/disorders/chiari/detail_chiari.htm	no clear indication that it usually causes intellectual and adaptive skills deficits	Linda Lunsford
2/28/2011	5/5/2011	Reject	Chromosome 9 p+	None found	Chromosomal	No	No		Based on the ODC criteria adopted 10/13/10 this submission has been rejected as a "condition similar to mental retardation" because the name of the condition returns no results in our research.	
6/23/2010	6/30/2010	Reject	Chromosome 18q Deletion	a chromosomal disorder resulting from a deletion of part of chromosome 18	Chromosomal	No	No	no information in our accepted sources; some info at: http://www.ulf.org/types/18q.html	no clear indication that it usually causes intellectual and adaptive skills deficits	Linda Lunsford
12/14/2010	1/21/2011	Reject	Cognitive (Disorder) NOS	disorders that are characterized by cognitive dysfunction presumed to be due to the direct physiological effect of a general medical condition that do not meet criteria for any of the specific deliriums, dementias, or amnesic	neither	No	No	DSM-IV TR	no specific cause and no diagnostic criteria	linda lunsford
	6/10/2010	Reject	Congenital Hydrocephalus	Hydrocephalus is due to a problem with the flow of cerebrospinal fluid (CSF), the liquid that surrounds the brain and spinal cord. The fluid brings nutrients to the brain, takes away waste from the brain, and acts as a cushion. This build up of fluid puts pressure on the brain, pushing the brain up against the skull and damaging or destroying brain tissues.	Affects the brain and CNS	No	No	MedlinePlus: http://www.nlm.nih.gov/medlineplus/ency/article/001571.htm	Most children with hydrocephalus that survive for 1 year will have a fairly normal life span. Approximately a third will have normal intellectual function,	Linda Lunsford
9/7/2010	10/28/2010	Reject	Congenital Rubella	Congenital rubella is a group of physical problems that occur in an infant when its mother is infected with the virus that causes German measles.	neurological	No	No	http://www.nlm.nih.gov/medlineplus/ency/article/001658.htm	all sources mention the risk of some intellectual impact (learning disabilities, developmental delays, mental retardation) but only one (MedicineNet) says that mental retardation is characteristic.	linda lunsford
2/3/2011	5/5/2011	Reject	Congenital Translocation of the X and Y Chromosome (with a break point on the X at XP 22.3 and Y at YQ 11.2)	None found	Chromosomal	No	No		Based on the ODC criteria adopted 10/13/10 this submission has been rejected as a "condition similar to mental retardation" because the name of the condition returns no results in our research.	linda lunsford

9/14/2010	12/3/2010	Accept	Cornelia de Lange Syndrome	characterized by slow growth before and after birth, intellectual disability that is usually severe to profound, skeletal abnormalities involving the arms and hands, and distinctive facial features	Chromosomal	Yes	Yes	http://ghr.nlm.nih.gov/condition/cornelia-de-lange-syndrome		linda lunsford
8/31/2010	11/5/2010	Accept	Cri du chat syndrome	Cri du chat syndrome is a group of symptoms that result from missing a piece of chromosome number 5. The syndrome's name is based on the infant's cry, which is high-pitched and sounds like a cat.	Chromosomal	Yes	Yes	http://ghr.nlm.nih.gov/condition/cri-du-chat-syndrome		linda lunsford
8/11/2010	9/17/2010	Reject	Dandy-Walker malformation	The key features of this syndrome are an enlargement of the fourth ventricle (a small channel that allows fluid to flow freely between the upper and lower areas of the brain and spinal cord), a partial or complete absence of the area of the brain between the two cerebellar hemispheres (cerebellar vermis), and cyst formation near the internal base of the skull. An increase in the size of the fluid spaces surrounding the brain as well as an increase in pressure may also be	neurological	No	No	http://www.ninds.nih.gov/disorders/dandywalker/dandywalker.htm	The effect of Dandy-Walker Syndrome on intellectual development is variable, with some children having normal cognition	linda lunsford
8/11/2010	9/17/2010	Reject	Diffuse Static Encephalopathy	No clear definition available	neurological	No	No	http://www.ninds.nih.gov/disorders/encephalopathy/encephalopathy.htm	No clear diagnosis; no listing on any of our acceptable WWW resources	linda lunsford
6/10/2010	8/2/2010	Accept	Down Syndrome	Down syndrome is a chromosomal condition that is associated with intellectual disability, a characteristic facial appearance, and poor muscle tone (hypotonia) in infancy.	Chromosomal	Yes	Yes	http://ghr.nlm.nih.gov/condition/down-syndrome		Linda Lunsford
6/29/2010	7/13/2010	Reject	Duchenne MD	Duchenne Muscular Dystrophy is a rapidly worsening form of muscular dystrophy.	Chromosomal	No	No	http://www.nlm.nih.gov/medlineplus/ency/article/000705.htm ; http://ghr.nlm.nih.gov/condition/duchenne-and-becker-muscular-dystrophy	primarily a musculo/skeletal disability, most resources do not mention intellectual impairment	Linda Lunsford
7/15/2010	7/29/2010	Reject	Fetal Alcohol Spectrum Disorders	FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.	neurological	No	No	http://www.fasdcenter.samhsa.gov/documents/WYNKDiagnosis_5_colorJA_new.pdf http://www.nih.gov/about/researchresultsforthepublic/FetalAlcohol.pdf	Fetal Alcohol Spectrum Disorder is an umbrella term describing a range of effects. It is not a diagnostic term.	Linda Lunsford
8/5/2010	8/17/2010	Accept	Fetal Alcohol Syndrome	The sum total of the damage done to the child before birth as a result of the mother drinking alcohol during pregnancy. Fetal alcohol syndrome (FAS) always involves brain damage, impaired growth, and head and face abnormalities.	neurological	Yes	Yes	http://www.nlm.nih.gov/medlineplus/ency/article/000911.htm		linda lunsford
7/8/2010	8/17/2010	Accept	Fragile X Syndrome - in males	Once thought of as a typical X-linked recessive condition, Fragile X is now understood as a family of disorders which affects both males and females. It differs from other X-linked conditions in three important ways: Both males and females can have fragile X syndrome (though females are usually more mildly affected)	Chromosomal	Yes	Yes	http://ghr.nlm.nih.gov/condition/fragile-x-syndrome	only the full spectrum of the disorder in males typically causes cognitive impairment	linda lunsford

7/8/2010	8/17/2010	Reject	Fragile X Syndrome - in females	Once thought of as a typical X-linked recessive condition, Fragile X is now understood as a family of disorders which affects both males and females. It differs from other X-linked conditions in three important ways: Both males and females can have fragile X syndrome (though females are usually more mildly affected).	Chromosomal	No	No	http://ghr.nlm.nih.gov/condition/fragile-x-syndrome	only the full spectrum of the disorder in males typically causes cognitive impairment	linda lunsford
12/14/2010	2/11/2011	Reject	Glycosylation Type IA	The chemical linkage of sugar molecules to proteins. ... may injure cytokines, cell receptors, the extracellular matrix, retinas, kidneys, nerves, and arteries, among other tissues.	Chromosomal	No	No	http://www.ncbi.nlm.nih.gov/books/NBK11110/	clinical presentation and course are highly variable	linda lunsford
12/2/2010	1/21/2011	Reject	Hypomelanosis of Ito	hypomelanosis (hi"po-mel"ə-no'sis) a deficiency of melanin in the tissues, especially in the skin	unknown	No	No	http://www.mercksource.com/pp/us/cns/cns_search_results.jsp?ip_text=Hypomelanosis+of+Ito&queryterm=Hypomelanosis+of+Ito&hitsPe	no evidence that it usually causes intellectual impairment	linda lunsford
9/8/2010	12/3/2010	Reject	Incontinentia Pigmenti	characterized by skin abnormalities that evolve throughout childhood and young adulthood.	Chromosomal	No	No	http://ghr.nlm.nih.gov/condition/incontinentia-pigmenti	Most people with incontinentia pigmenti have normal intelligence	
1/26/2011	3/3/2011	Accept	Kabuki Syndrome	An autosomal dominant disorder characterized by mild to moderate mental retardation...	Chromosomal	Yes	Yes	http://ghr.nlm.nih.gov/gene/MLL2		linda lunsford
8/11/2010	9/17/2010	Reject	Marfan syndrome	a disorder of the connective tissue and results in a variety of physical abnormalities	Chromosomal	No	No	http://vsearch.nlm.nih.gov/vivisimo/cgi-bin/query-meta?v%3Aproject=medlineplus&query=marfan		linda lunsford
7/26/2010	8/17/2010	Reject	Microcephaly		CNS	No	No	http://www.medterms.com/script/main/art.asp?articlekey=4373	microcephaly is a feature of some other condition; it is the other condition that may determine degree of impairment	linda lunsford
3/24/2011	5/5/2011	Reject	Mosaic Trisomy 13	Mosaic Trisomy 13 is a variation of Trisomy 13.	Chromosomal	No	No	http://ghr.nlm.nih.gov/condition/trisomy-13	The severity of mosaic trisomy 13 depends on the type and number of cells that have the extra chromosome. The physical features of mosaic trisomy 13 are often milder than those of full trisomy 13.	linda lunsford
7/22/2010	8/10/2010	Reject	Noonan Syndrome	Noonan syndrome is a genetic disorder that causes abnormal development of multiple parts of the body.	Chromosomal	No	No	http://ghr.nlm.nih.gov/condition/noonan-syndrome	"The majority of children diagnosed ... have normal intelligence."	Linda Lunsford
9/16/2010	11/6/2010	Reject	Ohdo Madokoro Sonoda syndrom	None found	Chromosomal	Unknown	Unknown	http://ghr.nlm.nih.gov/search?query=Ohdo+Madokoro+Sonoda+Syndrome&Search=Search	Base on the OCDC criteria adopted 10/13/10 this submission has been rejected as a "condition similar to mental retardation" because the name of the condition returns no results in our research.	linda lunsford
9/7/2010	11/6/2010	Reject	Organic Brain Syndrome	Organic Brain Syndrome is a term for a constellation of psychological or behavioral signs and symptoms associated with brain dysfunction of unknown or unspecified etiology. grouped	neurological	Unknown	Unknown	http://www.nlm.nih.gov/medlineplus/ency/article/001401.htm	it has no clear cause, diagnostic criteria, or characteristic symptoms	linda lunsford

8/9/2010	9/20/2010	Accept	Pallister-Killian mosaic syndrome	characterized by extremely weak muscle tone (hypotonia) in infancy and early childhood, intellectual disability, distinctive facial features, sparse hair, areas of unusual skin coloring (pigmentation), and other birth defects	Chromosomal	Yes	Yes	http://ghr.nlm.nih.gov/condition/pallister-killian-mosaic-syndrome		linda lunsford
10/10/2011	11/9/2011	Accept	Perisylvian Syndrome	neurological disorder characterized mainly by partial paralysis of muscles on both sides of the face, tongue, jaws, and throat; difficulties in speaking, chewing, and swallowing (dysphagia); and/or seizures (epilepsy).	neurological	Yes	Yes	http://rarediseases.info.nih.gov/GARD/Condition/6011/Bilateral_perisylvian_polymicrogyria.aspx		linda lunsford
5/24/2010	6/9/2010	Reject	Prader Willi Syndrome - being re-reviewed	Prader-Willi syndrome is a congenital (present from birth) disease that involves obesity, decreased muscle tone, decreased mental capacity, and sex glands that produce little or no hormones.	Chromosomal	As many as 40% have FSIQ above 70	No	Genetics Home Reference (2009): http://ghr.nlm.nih.gov/condition/prader-willi-syndrome	May not cause intellectual deficits and does not cause adaptive skills deficits	Linda Lunsford
5/28/2010	6/10/2010	Accept	Rett Syndrome	Rett syndrome is a neurodevelopmental disorder that affects girls almost exclusively. It is characterized by normal early growth and development followed by a slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures, and intellectual disability.	Chromosomal	Yes	Yes	Medline Plus: http://www.ninds.nih.gov/disorders/rett/detail_rett.htm		Linda Lunsford
4/4/2011	5/5/2011	Accept	rhizomelic chondrodysplasia punctata Type 1	Rhizomelic chondrodysplasia punctata is a condition that impairs the normal development of many parts of the body. The major features of this disorder include skeletal abnormalities, distinctive facial features, intellectual disability, and respiratory problems.	Chromosomal	Yes	Yes	http://ghr.nlm.nih.gov/condition/rhizomelic-chondrodysplasia-punctata		linda lunsford
3/17/2011	5/5/2011	Reject	Ring 21 Chromosome Abnormality	Rings: A portion of a chromosome has broken off and formed a circle or ring. This can happen with or without loss of genetic material.	Chromosomal	No	No		Based on the ODC criteria adopted 10/13/10 I believe this <u>is not</u> "condition similar to mental retardation" because the name of the condition returns no results in my research. It does not appear to be a "condition" per se but simply a description of a structural anomaly in a chromosome.	linda lunsford
	8/11/2011	Accept	Rubinstein-Taybi Syndrome	a condition characterized by short stature, moderate to severe intellectual disability, distinctive facial features, and broad thumbs and first toes	Chromosomal	Yes	Yes			linda lunsford
7/30/2010	8/12/2010	Accept	Sanfilippo Syndrome or Mucopolysaccharidosis	Sanfilippo syndrome is an inherited disease of metabolism that makes the body unable to properly break down long chains of sugar molecules called glycosaminoglycans (formerly called mucopolysaccharides)	CNS	Yes	Yes	http://www.nlm.nih.gov/medlineplus/ency/article/001210.htm		linda lunsford

12/6/2010	1/21/2011	Reject	Septo-Optic Dysplasia	Although its signs and symptoms vary, this condition is traditionally defined by three characteristic features: underdevelopment (hypoplasia) of the optic nerve, abnormal formation of structures along the midline of the brain, and pituitary hypoplasia	In most cases of septo-optic dysplasia, the cause of the disorder is unknown.	no	No	http://www.ninds.nih.gov/disorders/septo_optic_dysplasia/septo_optic_dysplasia.htm	no evidence that it usually causes intellectual impairment	linda lunsford
8/5/2010	9/2/2010	Reject	Shaken Baby Syndrome - being re-reviewd	Shaken baby syndrome is a type of inflicted traumatic brain injury that happens when a baby is violently shaken.	CNS	No	No	http://www.medicinenet.com/shaken_baby_syndrome/article.htm	Diagnosis is circumstantial and the likelihood of intellectual or adaptive deficits depends on the type and severity of the injury. Most children with intellectual deficits as a result of SBS would be considered under MR.	linda lunsford
5/28/2010	6/10/2010	Accept	Smith-Magenis Syndrome	Smith-Magenis syndrome is a developmental disorder that affects many parts of the body. The major features of this condition include mild to moderate intellectual disability, delayed speech and language skills, distinctive facial features, sleep disturbances, and behavioral problems	Chromosomal	Yes	Yes	Genetics Home Reference: http://ghr.nlm.nih.gov/condition/smith-magenis-syndrome		Linda Lunsford
8/5/2010	9/14/2010	Reject	Spina Bifida	characterized by the incomplete development of the brain, spinal cord, and/or meninges (the protective covering around the brain and spinal cord)	neurological	No	Yes	(http://www.ninds.nih.gov/disorders/spina_bifida/detail_spina_bifida.htm)	Complications of spina bifida can range from minor physical problems to severe physical and mental disabilities. It is important to note, however, that most people with spina bifida are of normal intelligence.	linda lunsford
5/25/2010	6/9/2010	Reject	Static Encephalopathy	Encephalopathy is a term for any diffuse disease of the brain that alters brain function or structure. Encephalopathy may be caused by infectious agent (bacteria, virus, or prion), metabolic or mitochondrial dysfunction, brain tumor or increased pressure in the skull, prolonged exposure to toxic elements (including solvents, drugs, radiation, paints, industrial chemicals, and certain metals), chronic progressive trauma, poor nutrition, or lack of oxygen or blood flow to the brain. The hallmark of encephalopathy is an altered mental		No	No	National Institutes of Health: http://www.ninds.nih.gov/disorders/encephalopathy/encephalopathy.htm	No clear diagnosis; no listing on any of our acceptable WWW resources	Linda Lunsford
7/29/2010	8/17/2010	Accept	Sturge-Weber Syndrome	Sturge-Weber syndrome is a neurological disorder indicated at birth by seizures accompanied by a large port-wine stain birthmark on the forehead and upper eyelid of one side of the face.	neurological	Yes	Yes	http://www.ninds.nih.gov/disorders/sturge_weber/sturge_weber.htm		linda lunsford
12/7/2010	2/1/2011	Reject	Transverse Myelitis	a neurological disorder caused by inflammation across both sides of one level, or segment, of the spinal cord	neurological	No	No	http://www.ninds.nih.gov/disorders/transversemyelitis/detail_transversemyelitis.htm	no indication that it ever causes cognitive impairment	linda lunsford
8/31/2010	9/17/2010	Reject	Traumatic Brain Injury (TBI)	Traumatic brain injury (TBI), a form of acquired brain injury, occurs when a sudden trauma causes damage to the brain.	neurological	No	No	http://www.mercksource.com/pp/us/cns/cns_merckmanual_frameset.jsp?QzpgzEzhttpzCzzSzzSzwwwzPzmerckzPzcomzSzmmhezSzsec06zSzch087zSzch087azPzhtml	many people, especially children, can recover fully from TBI	linda lunsford

9/2/2010	9/17/2010	Reject	Triple X Syndrome	Triple X syndrome, also called trisomy X or 47,XXX, is characterized by the presence of an additional X chromosome in each of a female's cells.	Chromosomal	No	No	http://www.mayoclinic.com/health/triple-x-syndrome/DS01090/METHOD=print	Many women with triple X syndrome have no symptoms or only mild symptoms.	linda lunsford
8/31/2010	11/6/2010	Reject	Trisomy 2p	None found	Chromosomal	Unknown	Unknown	http://ghr.nlm.nih.gov/search?query=Chromosome+2p+duplication+syndrome&Search=Search	Base on the OCDC criteria adopted 10/13/10 this submission has been rejected as a "condition similar to mental retardation" because the name of the condition returns no results in our research.	linda lunsford
12/20/2011	12/22/2010	Reject	Trisomy 8 Mosaicism	Trisomy 8 occurs when cells have three copies of chromosome 8 instead of the usual two copies.	Chromosomal	No	No	http://ghr.nlm.nih.gov/chromosome/8	While it <u>may</u> cause intellectual impairment in some cases the nature of chromosomal mosaicism is that it is unpredictable and the severity of the condition depends largely on the percentage of abnormal cells	linda lunsford
12/7/2010	2/1/2011	Reject	Trisomy for 5q and Monosomic for 9p (Chromosome Study) Chromosome Imbalance	None found	Chromosomal	Unknown	Unknown	http://ghr.nlm.nih.gov/search?query=Trisomy+for+5q+and+Monosomic+for+9p+%28Chromosome+Study%29+Chromosome+Imbalance&Search=Search	there is no evidence that Trisomy for 5q and Monosomic for 9p (Chromosome Study) Chromosome Imbalance constitutes a specific, definable condition for the application of the "other condition" criteria	
10/5/2010	11/5/2010	Accept	Tuberous Sclerosis		Chromosomal	Yes	Yes	http://www.nlm.nih.gov/medlineplus/ency/article/000787.htm		linda lunsford
7/15/2010	7/28/2010	Reject	Velo Cardio Facial Syndrome	VCFS is characterized by a combination of medical problems that vary from child to child. These medical problems include: cleft palate, or an opening in the roof of the mouth, and other differences in the palate; heart defects; problems fighting infection; low calcium levels; differences in the way the kidneys are formed or work; a characteristic facial appearance; learning problems; and speech and feeding problems.	Chromosomal	Yes	No	http://ghr.nlm.nih.gov/condition/22q112-deletion-syndrome ; http://ghr.nlm.nih.gov/condition/22q112-deletion-syndrome http://www.medterms.com/script/main/art.asp?articlekey=5972 http://www.mercksource.com/pp/us/cns/cns_hl_dorlands_split.jsp?pg=/ppdocs/us/common/dorlands/dorland/nine/100016720.ht	Primarily a medical condition; no indication of adaptive skills deficits	Linda Lunsford
7/13/2010	8/17/2010	Accept	Warkany Syndrome	Trisomy 8 occurs when cells have three copies of chromosome 8 instead of the usual two copies. Full trisomy 8, which occurs when all of the body's cells contain an extra copy of chromosome 8, is not compatible with life. A similar but less severe condition called mosaic trisomy 8 occurs when only some of the body's cells have an extra copy of	Chromosomal	Yes	Yes	http://ghr.nlm.nih.gov/chromosome/8		linda lunsford
9/2/2010	9/20/2010	Accept	Williams Syndrome	Williams syndrome is characterized by mild to moderate intellectual disability or learning problems, unique personality characteristics, distinctive facial features, and heart and blood vessel (cardiovascular) problems.	Chromosomal	Yes	Yes	http://ghr.nlm.nih.gov/condition/williams-syndrome		linda lunsford

Exhibit B

**ACCESS AGREEMENT BETWEEN
WASHINGTON PROTECTION AND ADVOCACY SYSTEM, INC.,
AND
THE DIVISION OF DEVELOPMENTAL DISABILITIES,
DEPARTMENT OF SOCIAL AND HEALTH SERVICES.**

This agreement is entered into by the Washington Protection and Advocacy System, Inc. (hereinafter WPAS), the protection and advocacy system authorized pursuant to the Developmental Disabilities Assistance and Bill of Rights Act of 1975, 42 U.S.C. sec. 6000, et seq., to investigate alleged incidents of abuse, neglect, and rights violations of persons with developmental disabilities, and the Division of Developmental Disabilities (hereinafter DDD) of the Department of Social and Health Services, for the purpose of clarifying the rights and responsibilities of WPAS with respect to its access to individuals with developmental disabilities, clients, programs, and records.

The Department of Social and Health Services, specifically DDD, is responsible for providing services to individuals with developmental disabilities, to the extent funding is available. In providing those services, DDD must protect the confidentiality of records and information regarding those individuals pursuant to the state and federal confidentiality laws.

WPAS is charged by federal law to protect the legal and human rights of individuals with developmental disabilities. WPAS provides legal and related advocacy services to meet that obligation. WPAS is also required to maintain the confidentiality of records and information regarding individuals with developmental disabilities consistent with 42 U.S.C. § 6000, et seq.

This agreement governs the access of Washington Protection and Advocacy System to DDD employees who do not work in Residential Habilitation Centers (RHCs) and records maintained by DDD which are associated with individuals with developmental disabilities living outside of RHCs.

Federal laws and regulations also provide WPAS with access to community programs and individuals with developmental disabilities served by DDD contracted providers. DDD will work with community providers and WPAS to arrive at an agreement governing access to DDD contracted programs and the people served by them.

I. General.

A. That all terms used in this agreement which are defined in the Developmental Disabilities Assistance and Bill of Rights Act of 1975, 42 U.S.C. § 6000, et seq., will have the meaning given to them in the Act, unless otherwise stated in this agreement.

B. This agreement is intended to carry out the provisions of the Developmental Disabilities Assistance and Bill of Rights Act of 1975, 42 U.S.C. § 6000, et seq., and therefore, if this agreement is or becomes inconsistent with the Act or the implementing regulations promulgated thereto, the terms of the Act and its implementing regulations will control.

C. If any provision of the agreement is held invalid, the parties intend that the remainder of the agreement not be affected.

II. Definitions.

A. Actively Aggressive: means that the individual with developmental disabilities is assaulting others or is threatening to do so, or the individual with developmental disabilities is actively harming him or her self.

B. Client Services: means legal representation. The term does not include monitoring and observation.

C. Complaint: as defined in 45 CFR 1386, or hereinafter amended, includes, but is not limited to, any report or communication, whether formal or informal, written or oral, received by WPAS including media accounts, newspaper articles, telephone calls (including anonymous calls), from any source alleging abuse or neglect of an individual with a developmental disability.

D. DDD Consumer: means an individual with a developmental disability receiving support from a program funded by DDD. The term includes DDD consumers who have died or whose whereabouts are unknown. See 45 CFR 1386.22(a)(2).

E. DDD Employees: includes those individuals who are employed by DDD or who volunteer for DDD to provide services to individuals with developmental disabilities.

F. Emergencies: means actions, omissions, or conditions that immediately threaten an individual with a developmental disability's health, life or well being.

G. Individual with a Developmental Disability: means individuals with developmental disabilities in the process of applying for or who have been found eligible for services from DDD.

H. Monitoring: means unaccompanied access to all residents of a program at reasonable times, which at a minimum shall include normal working and visiting hours to ensure program compliance with respect to the rights and safety of DDD consumers. See 45 C.F.R. §1386.22(g).

I. Probable Cause: as defined in 45 CFR 1386, or hereinafter amended, means a reasonable ground for belief that an individual with developmental disabilities has been, or may be, subject to abuse or neglect. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse and neglect.

J. Program: consistent with the definition of "facility" in 45 CFR 1386.19 includes any setting that provides care, treatment services and habilitation, even if only "as needed" or under a contractual arrangement. Programs include, but are not limited to, community living arrangements (e.g., group homes, adult family homes, congregate care facilities, boarding homes, individual residences and apartments), day programs, juvenile detention centers, nursing homes, homeless shelters, jails and prisons.

K. Provider: means those individuals/corporations with whom DDD contracts to provide services to DDD consumers, including but not limited to behavioral management services, family support services, vocational support services, sheltered employment, tenant support, intensive tenant support, alternative living, supported living, group home, adult family home, and congregate care facilities, chore services, medicaid personal care and other personal assistance services.

L. Provider Employee: includes those individuals who are employed by a provider or who volunteer for a provider to provide services to individuals with developmental disabilities.

M. Records: as defined in 42 U.S.C. § 6042 and 45 CFR 1386(22)(b), or hereinafter amended, reports prepared by any state staff or reports prepared by an agency charged with investigating reports of incidents of abuse, neglect, injury, or death that describe incidents of abuse, neglect, injury, or death occurring at a facility, investigative documents and discharge planning records. The term records also includes DDD consumer abuse and neglect committee reports but does not include peer review death reports, attorney work product, and records which are otherwise privileged under state or federal law.

N. Regular Program Activity: includes work assignments, education programs, therapy, health services, and daily living activities.

O. SOLA: means the DDD consumer support program, State Operated Living Alternative.

P. WPAS Client(s):

(1) Individuals with developmental disabilities who do not have a guardian or legal representative and who indicate either orally or in writing to a WPAS employee that they want WPAS to represent them.

(2) Individuals with developmental disabilities without guardians who are unable to communicate their wishes regarding protection and advocacy services when WPAS has received a complaint of abuse and/or neglect about the individual with a disability, or WPAS determines that there is probable cause to believe that the individual with a developmental disability has been abused or neglected.

(3) Individuals with developmental disabilities who have a guardian or legal representative where the guardian or legal representative has consented to the representation in writing.

(4) Individuals with developmental disabilities whose guardian or legal representative fails or refuses to act on behalf of the individual with a developmental disability, despite being contacted by WPAS, after a court has determined that the guardian has failed or refuses to act.

(5) A WPAS client does not include those instances where WPAS represents the guardian. WPAS shall notify the DDD Regional Administrator or designee in writing that it represents the individual with developmental disabilities and forward a copy of that notice to either the guardian or the individual with developmental disabilities.

Q. WPAS Employees: includes paid employees and volunteer employees as identified by WPAS. Each employee shall carry WPAS identification.

III. Access to Programs.

A. DDD will not obstruct WPAS access to programs when consistent with the law and will ensure that SOLA and other programs staffed by DDD employees will comply with this agreement. For programs which contract with DDD to provide services, DDD will not

obstruct WPAS access to programs when consistent with the law, but WPAS will assume primary responsibility for enforcing its access rights. WPAS will attempt to resolve access issues at the lowest level possible. In cases where there is danger of imminent or continuing harm to an individual with developmental disabilities WPAS will report the occurrence to DDD, consistent with the Washington State Bar Association Rules of Professional Responsibility and other applicable state law. In those cases and where there is a pattern of failure to provide access for WPAS to a program or DDD consumers, WPAS will report this failure to DDD, and DDD will respond by investigating the allegation of failure to provide access and will take appropriate actions.

B. WPAS staff will identify themselves to any staff present when they arrive at a program by showing a WPAS photo identification badge. WPAS shall provide the DDD director with a list of employees and their pictures by July 1, 1997, and WPAS shall update this list as necessary.

C. WPAS shall have access to SOLAs and other programs staffed by DDD employees as specified in this section. This agreement does not affect the right of an individual with a developmental disability served by such a program who owns or rents his or her own home to deny access to WPAS to his or her home. However, DDD employees do not have the right to deny WPAS access to programs or the residences of individuals who are served by programs.

D. WPAS staff shall have access to all programs when WPAS has received a complaint or has probable cause to believe that an incident of abuse, neglect, or other rights violation has occurred;

E. WPAS staff shall have access to all living areas of SOLAs and other programs staffed by DDD employees during regular business hours for the purpose of providing information on legal rights and self advocacy to the individuals with disabilities who participate in the program. During the course of such access, WPAS staff shall be allowed to engage in informal discussions with the individuals with disabilities, out of the presence of DDD employees or others, in an area that affords privacy.

F. WPAS staff may visit any location where residents are served by DDD employees, where the purpose is observation or monitoring compliance with respect to the rights and safety of service recipients (CFR 1386.22(g)(2)). Such observation and monitoring activities need not be limited to clients of WPAS, and WPAS staff shall not be required to schedule or give prior notice of such visits to DDD employees, provided that WPAS has the permission of a DDD consumer. WPAS staff shall be permitted to monitor the program without an accompanying DDD employee. WPAS staff shall conduct all monitoring activities in a manner which is respectful of the privacy of the individuals with disabilities who reside in the monitored program.

IV. Access to Individuals with Developmental Disabilities.

A. WPAS staff will be provided access to their clients in the same manner as such access is provided to privately retained and/or court appointed attorneys. DDD shall assist and support the professional relationship between WPAS and its clients. Written consent for such access is not required.

B. WPAS recognizes that all individuals with developmental disabilities have the right to refuse to talk with WPAS, to have a third party present during the interview, or to reschedule the appointment for a more convenient time. WPAS shall advise their clients and other individuals with developmental disabilities with whom they have contact of these

rights before each meeting. A person who does not wish to talk with WPAS staff shall be allowed to communicate this directly and privately to WPAS staff unless he or she overtly manifests fear of being alone with the WPAS staff. When the individual with a developmental disability overtly manifests such fear by words or behavior, WPAS shall respect that person's desires and not meet alone with that person.

C. WPAS will encourage its clients and other individuals with developmental disabilities to notify DDD and/or providers of complaints regarding DDD services and to resolve those complaints through any existing dispute resolution process.

D. WPAS staff shall comply with all safety and security requirements of DDD. DDD will communicate these requirements to WPAS staff.

E. DDD employees shall not interfere with WPAS staff in obtaining a private space for meetings between WPAS staff and individuals with developmental disabilities. Private space does not mean a corner of a common area room or other location which would afford other residents and DDD employees open access to WPAS employees in living areas or on the grounds. DDD employees shall respect the confidentiality needs of the individual with a developmental disability and WPAS. Where an individual with a developmental disability indicates that he or she does not want to meet in a private space, WPAS staff will respect this request.

F. WPAS staff will not be required to schedule visits with DDD employees in advance of their visits. However, WPAS staff may contact DDD employees to do so if access to a WPAS client or other individual with a developmental disability will be facilitated due to the individual's daily activities.

G. WPAS staff shall have the right to unaccompanied access to any SOLA or program staffed by DDD employees, and access to any individual WPAS client or DD consumer they are authorized to serve, subject to the following limitations:

(1) While WPAS need not notify the DDD employees prior to meeting with its client or DDD consumer, WPAS agrees not to disturb a client or DDD consumer if the WPAS employee arrives at the residence or other building in which the client or DDD consumer is served and the client or DDD consumer is engaged in regularly scheduled program activity. In such case, WPAS staff will be permitted to observe or otherwise verify the programming without disturbing it. If WPAS staff presence disturbs or is objected to by the WPAS client or any other DDD consumer who is present, WPAS staff shall make arrangements to meet with the WPAS client or DDD consumer at a later time. Where consulted prior to making an appointment, DDD employees will cooperate with WPAS staff in making scheduling arrangements. The WPAS employee shall not disturb nor interrupt the activity. If the activity is confidential, WPAS shall obtain the client or DDD consumer's permission to observe the activity or shall respect the client or DDD consumer's right to privacy. WPAS staff will then either wait until the activity is completed or reschedule the visit at a time that is mutually agreeable to WPAS staff and its individual client or DDD consumer, no later than 48 hours later.

(2) If the WPAS employee arrives for a meeting with a client or DDD consumer and the individual is actively aggressive, in programming to address this behavior, or receiving "one-to-one" supervision, in such a situation, WPAS staff will be permitted to observe the individual from a safe distance or otherwise verify that the individual is actively aggressive. WPAS staff will then either:

(a) wait until the individual's aggressive behavior has stopped and be permitted to meet with the individual privately while DDD employees remain in viewing distance; unless such distance would place the individual with developmental disabilities at serious risk of harm based on that individual's documented behavioral issues; if the individual would be at serious risk of harm, WPAS and DDD shall work cooperatively to address WPAS need for confidentiality with the individual's need for safety; provided that any such interview does not interfere with the individual's Behavior Support Program, Individual Program Plan, Individual Service Plan, or other program plan, nor interfere with staffing needs for other individuals with developmental disabilities; or

(b) reschedule the visit at a time mutually agreeable to WPAS and DDD employees, but no later than forty-eight (48) hours;

(c) if the WPAS staff is notified that an individual is either actively aggressive or receiving one-to-one supervision and if knowing this the staff chooses to meet with the individual, WPAS agrees to release, indemnify, and hold DDD, DSHS, the State and its employees, agents, officers, and servants harmless for any injuries that occur from any claims or cause of action asserted by any WPAS employee or agent who is injured as a result of any act committed by an individual with developmental disabilities except that those circumstances where DDD employees' willful misconduct is the proximate cause of the injury to WPAS' employee or agent. WPAS agrees that its staff shall sign a statement to this effect prior to requesting to meet with any such individual. If the WPAS staff refuses to sign such an agreement, DDD employees may deny the WPAS staff access to the individual until such time as DDD employees determine that safety to the WPAS staff is no longer an issue. When a WPAS staff member elects to meet with an individual who is actively aggressive, it is neither negligent nor willful misconduct for a state employee to allow the meeting to take place.

H. All individuals with developmental disabilities who wish to contact WPAS staff shall be provided uncensored access to writing materials, WPAS' address and toll-free telephone number, a stamped envelope, and/or access to a telephone for private conversations without monitoring by or permission from DDD employees.

I. SOLAs and programs staffed by DDD employees shall permit individuals with developmental disabilities to set appointments with WPAS staff at times agreeable to both the individual with a developmental disability and WPAS staff. If the DDD employees know that a meeting with a DDD consumer will be disruptive of the DDD consumer's regular program activity, WPAS staff shall be informed of this and allowed to reschedule the appointment in order to meet with the DDD consumer so that the appointment does not disrupt his or her regular activity.

V. Access to Records of Individuals with Developmental Disabilities.

A. WPAS has access to records as provided in 42 U.S.C. § 6042, et seq. WPAS has legal authority to review an individual with developmental disabilities' records only when there is consent or, if a DDD consumer is unable to consent, there is a complaint or probable cause to believe a DDD consumer has suffered abuse or neglect. WPAS has no general right to review records except in these circumstances.

B. Upon receiving a valid, written consent, DDD will have 48 hours in which to schedule an appointment with WPAS so that it may come to the record location to review specified records. DDD will verify that WPAS has received consent to view such records, or if the DDD consumer is unable to consent and there is no guardian to consent, that there is a complaint or probable cause to believe the DDD consumer has suffered abuse or neglect. DDD shall make the requested records within its possession available within five working days from the date the request is made.

C. WPAS may access records of:

(1) any DDD consumer if he or she consents, or if he or she has a legal guardian with the power to consent for the DDD consumer and that guardian consents;

a) the DDD consumer or guardian shall give written authorization for access on a form approved by WPAS and DDD jointly.

(2) any DDD consumer:

a) who by reason of his or her mental or physical condition is unable to authorize WPAS to have access to their records;

b) who does not have a legal guardian, conservator, or other legal representative, or for whom the legal guardian is the state; and

c) with respect to whom a complaint has been received by WPAS or with respect to whom, as a result of monitoring or other activities there is probable cause to believe that such individual has been subject to abuse or neglect.

d) If records are requested pursuant to this section, the request shall be in writing and will state that the resident, by reason of his or her mental or physical condition is unable to authorize WPAS to have access to his or her records, does not have a legal representative, and that a complaint has been received by WPAS with respect to the DDD consumer or that there is probable cause to believe the resident has been subjected to abuse or neglect. The DDD case manager will make a determination regarding whether a DDD consumer is able to consent to access within 3 working days, except in case of an emergency.

(3) In the case of a resident who has a legal guardian, and upon request by WPAS, DDD will provide WPAS with the name, address and telephone number of the legal guardian by 5 p.m. the next business day so that WPAS can contact such representative and offer its assistance. If the guardian has been contacted by WPAS and failed or refused to act on behalf of the individual WPAS has received a complaint sufficiently that sufficiently identifies the individual or WPAS has probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, WPAS shall obtain court approval for such access.

a) If a guardian refuses to consent to allow WPAS access to records, and WPAS still wants access, WPAS will file a lawsuit to access the records and allow a court to determine whether the guardian has failed or refused to act on behalf of the DDD consumer. WPAS agrees to provide legal notice to DDD of any such proceeding. If the guardian refuses to provide written

consent for WPAS to access the records, DDD shall not make the records available absent a court order.

b) WPAS shall attempt to contact the guardian to obtain consent. Unless an emergency exists, then WPAS shall contact the standby guardian if one has been designated. If no standby guardian is appointed and the guardian is unavailable, and WPAS determines that the DDD consumer is at risk of serious injury or death, DDD shall make the records available to WPAS to review.

D. WPAS staff may review the requested records within normal business hours in the building or room in which such records are provided. A DDD employee may remain in the room while the records are viewed. Under no circumstances may WPAS staff remove the original records, or any part thereof, from the room where they are viewed.

E. WPAS agrees to reimburse DDD for the costs of copies at the same rate charged for public disclosure requests, currently \$.15 per page. When feasible, copies will be provided on the day the copies are requested. If that is not possible, DDD will make the copies available within 10 days of the request.

F. WPAS shall request guardian information or access to DDD consumer records of the DDD Regional Administrator of the region in which the DDD consumer resides. Thereafter, their contact regarding that DDD consumer shall be the regional administrator, or his or her designee. DDD shall provide WPAS a list with contact information for purposes of access to records. DDD agrees to update that list at least annually.

G. In order to access DDD records, WPAS will send a written request directly to the DDD Regional Administrator or designee in custody of the records. In the request, WPAS will identify the individual whose records it seeks. WPAS need not identify the individual by name, but must sufficiently identify the individual so that the person reviewing the request can determine whose records are being sought. WPAS will specify which records it wants and for which time periods. WPAS will also indicate that it has received a complaint concerning the individual so that it has probable cause to believe the individual has suffered abuse or neglect. WPAS need not further specify the nature of the complaint nor who made the complaint.

H. In the event DDD denies access to records pursuant to a request, WPAS staff may request that the denial be in writing and include the reason for the denial.

I. WPAS will limit its request to records it considers necessary to accomplish its investigation. DDD may request that WPAS specifically identify the records that it is seeking if the request is too broad or voluminous.

VI. Outreach.

A. All individuals with developmental disabilities shall have access to WPAS staff for the purpose of obtaining information about their legal rights and self-advocacy. WPAS staff shall be allowed to engage in informal discussions with DDD consumers who wish to speak to them out of the presence of DDD employees in an area that affords privacy.

B. WPAS may have regularly scheduled information/training sessions for DDD consumers and parents/guardians/family members regarding WPAS' services and individual rights. DDD employees may attend outreach and scheduled information sessions only with advance written permission of WPAS staff.

C. DDD agrees to give WPAS a list of all current DDD consumers and their addresses. DDD will provide WPAS an updated list annually.

D. DDD agrees to provide DDD consumers with notice of WPAS services at the time of application for DDD services. WPAS will provide DDD with copies of their brochure and/or any other information they want DDD to distribute at that time.

E. DDD agrees to require contractors to comply with 42 U.S.C. §6000 et seq. and 45 C.F.R. Parts 1385-86 by including the requirement in contracts. Current contracts will be amended to include this requirement when they are renewed.

VII. Authority to Investigate Allegations of Abuse and Neglect.

A. WPAS shall have unaccompanied reasonable access to DDD consumers and facilities when necessary to conduct a full investigation of an incident of abuse or neglect. This access shall include the opportunity to interview any individual with a developmental disability, any DDD or provider employee, or any other person who might be reasonably believed by WPAS to have knowledge of the incident under investigation; and to review what WPAS is entitled to review pursuant to this agreement. WPAS shall be permitted to do its own investigation of allegations of abuse or neglect regardless of any pending action or investigation by the State or any other individual or entity.

B. WPAS' investigations shall not interfere with any other ongoing investigation. WPAS employees shall not visit areas at times that would violate any person's right to privacy.

C. DDD shall allow and encourage all employees and providers to talk openly with WPAS employees. WPAS will not ask staff to disrupt their work schedules or responsibilities to talk with WPAS. Except in cases of emergency, WPAS will schedule appointments with staff in advance.

D. While DDD and provider employees shall be encouraged to cooperate with WPAS, employees have the right to refuse to talk with WPAS. WPAS shall notify employees of that right prior to any attempt to interview them.

E. Any complaint concerning WPAS staff shall be immediately brought to the attention of the WPAS Executive Director or his or her designee. Upon receipt of a complaint, the WPAS Executive Director or his or her designee shall conduct an investigation and submit a written response to the State within fourteen (14) days in an effort to resolve any complaints as expediently as possible. DDD reserves the right to file formal charges if the behavior places a DDD consumer's health or safety at risk.

F. WPAS shall inform DDD and providers, in writing, of its findings and concerns upon completion of any investigation activity undertaken pursuant to its authority under 42 U.S.C. § 6000 et seq., and the access rights granted to WPAS in this agreement, in an effort to resolve DDD consumer complaints or concerns prior to commencing litigation, unless WPAS believe that such delay would result in serious injury or harm to the DDD consumer.

VIII. Implementation of the Agreement.

A. The DDD Director shall ensure that each supervisor will conduct an annual meeting with his or her staff to provide information regarding the parties' rights and responsibilities under this agreement. The DDD director shall ensure that each employee of DDD has read

and signed a copy of a form indicating that they have read this agreement at the time of hire and at the time of his/her annual evaluation. DDD and WPAS shall develop a mutually agreed to summary of this agreement for use in informing DDD employees of the parties' rights and responsibilities. When DDD and WPAS develop and agree regarding the content of this summary, DDD employees shall be required to read the summary, rather than reading this agreement, and acknowledge that they read and understood the summary with a signature.

B. The agreement is effective as of the date it is signed.

C. DDD agrees that having an agreement in place that would govern WPAS and DDD provider relationships is appropriate. This agreement will affect contractual relationships, so it will be negotiated with providers prior to implementation. This negotiation will take place during the 1997-1998 provider contract negotiations. DDD will request WPAS review the proposed contract language prior to contract signing by DDD. The goal of this negotiation process will be to arrive at an agreement which implements the federal statutory and regulatory requirements in a manner consistent with the provision of quality, individualized services and supports to people with developmental disabilities living in the community.

D. The DDD director will make changes as necessary to implement this agreement by September 1, 1997, and prior to implementing changes will confer with WPAS.

E. WPAS and DDD agree to work together to assist providers in becoming familiar with WPAS access to programs. DDD agrees to host a forum in each region to familiarize providers with the access provisions. WPAS agrees to make staff available as presenters at regional forums, and otherwise as mutually agreed to with providers. DDD will distribute to providers a summary of the access provisions. This summary will be prepared by WPAS, and will be subject to the review and approval of DDD prior to distribution.

IX. Miscellaneous.

A. WPAS agrees that its staff shall not give medical advice and shall not engage in the practice of medicine. It is WPAS' intent and purpose to give legal advice. For example, WPAS will not tell DDD consumers not to take medication or that medications are wrong for them. WPAS will not discourage individuals with developmental disabilities from participating in programs or activities. WPAS may explain DDD consumer legal rights including the right to informed consent, their right to be told of the risks and benefits of medication or medical procedures, their right to refuse to take medications and the procedure to follow if the DDD consumer does not wish to take medications, and their right to refuse to participate in experimental programs or research, all as guaranteed under state and federal law.

B. WPAS agrees that there are some DDD consumers who are identified as medically fragile or to have behavioral concerns that require constant monitoring. If WPAS requests a meeting with such a DDD consumer and DDD determines that the DDD consumer cannot be left unsupervised with a WPAS employee, a DDD or provider employee shall be present during any meetings. If DDD consumers are hospitalized due to medical conditions, DDD or provider employees may remain within viewing distance if necessary for the DDD consumer's health and safety. The employees will not interfere with the meeting except for medical reasons and will respect the DDD consumer's privacy to the extent possible given his or her medical needs.

C. This agreement delineates the usual process by which WPAS and DDD will work together. In some situations, it may be necessary to amend these procedures. WPAS and DDD may agree to modify these procedures as necessary for any particular situation.

X. Dispute Resolution.

A. WPAS and DDD agree that informal resolution of disputes is preferred. If WPAS staff and the DDD Regional Administrator or designee are unable to agree about an issue regarding interpretation or application of this agreement, they will request the WPAS Executive Director and the DDD Director review the situation and attempt to resolve the disagreement.

B. The Directors Meeting and Mediation process are mandatory for both parties. The only exception to this term of the agreement is where WPAS, in good faith, has probable cause to believe that there are exigent circumstances warranting immediate access. Such circumstances are defined as "emergencies" as defined in the access agreements. In such cases, the WPAS Executive Director or his or her designee shall contact the Director of the Division of Developmental Disabilities or his or her designee; and/or Office of the Attorney General to attempt to resolve the dispute. If the exigent access dispute is not resolved by the end of the following business day, WPAS may immediately take any necessary legal action, including seeking a temporary restraining order and preliminary injunction or an order to show cause in order to secure the necessary access without going through the ADR process discussed herein. When WPAS does take such action, it shall give the Office of the Attorney General advance notice of such action by telephone and facsimile.

C. In the event that there is an access dispute regarding any aspect of the Access Agreements between WPAS and DDD (Community), the aggrieved party shall send written notice to the director of the other party (e.g. WPAS Executive Director, the Director of DDD, or their designees) of the dispute and the desire to meet to attempt to resolve the dispute. The DDD director (or his/her designee) shall meet with the WPAS Executive Director (or his/her designee) within ten days after receiving written notice from the aggrieved party. The date of receipt of notice shall be in accordance with Civil Rule 6 of the Washington Court Rules. The meeting may take place in person or telephonically. The parties have the right to bring their counsel to the directors meeting, however it is the preference of the parties not to have their counsel present. In the event a party intends to have his or her counsel present, that party will advise the other party of this intent in advance of the meeting. However, when either director (or his or her designee) is an attorney, it will be understood and expected that the other director may have his or her attorney present without prior notice.

D. In the event that the access issues are not resolved by a meeting between the Director/CEO and Executive Director of WPAS or their designees, the parties agree to attempt to resolve the dispute through mediation absent exigent circumstances as described in paragraph 1. An available mediator from the mutually agreed upon Mediator Panel list as described below will be used to conduct the mediation.

Mediation will be scheduled to occur as soon as possible following the directors meeting, but will occur no later than 30 days from the time mediation is agreed upon by the parties, absent written agreement by both parties to extend this timeline. The mediation may take place telephonically or in any manner the mediator believes will be efficient and conducive to a productive mediation. If, at any time during the mediation, either party declares an impasse, the mediation will end. The parties are then encouraged, but not

required, to arbitrate the dispute. The costs of mediation shall be borne equally by the parties. If no litigation results within 90 days of the completion of mediation, WPAS shall withdraw its access request. Nothing, however, prevents WPAS from renewing its request in the future should that become necessary. In such event WPAS renews the request, and that request is denied by the State, the ADR process will begin again.

E. Within 90 days of the execution of this agreement, the parties shall select a panel of at least 4 mutually agreeable mediators. There will be two separate lists: one for WPAS and DDD and one for WPAS and the MHD. The parties agree that any one of the selected panel members will mediate all disputes related to the Access Agreement. However, the parties will rotate the order of contacting the panel members for each mediation in a nonstrategical manner.

In order to select this panel, within 60 days of execution of this agreement, the parties will each propose at least 4 mediators. The parties will exchange, via fax, their list of proposed mediators and the mediators' curriculum vitae and any other necessary facts such as cost, mediation rules, etc. If the parties cannot agree upon at least 4 mediators from the first exchange of lists, the parties will exchange additional lists of mediators until an agreement can be reached. However, a final agreement must be reached no later than 90 days from the date of the settlement agreement of this case absent written agreement for an extension of a specific amount of time.

Any party may strike a mediator from the list except that a party may not strike a mediator from the panel once the mediation process has been initiated to resolve a dispute. If a party strikes a mediator from the panel, that mediator will be replaced by another mediator using the same mediator selection process as described above.

F. In the event that the access issues are not resolved through mediation, the parties may agree to attempt to resolve the dispute through arbitration. Written agreement to proceed to arbitration must be made within five working days of the completion of mediation described in Section B. An available arbitrator from the mutually agreed upon Arbitrator Panel list, as described below, will be used to conduct the arbitration of the dispute. Arbitration will be scheduled to occur as soon as possible, but will occur no later than 45 days from the time arbitration is agreed upon by the parties, absent written agreement by both parties to extend this timeline. Prior to the time of final agreement to arbitrate the dispute, the parties shall agree in writing whether the arbitration decision will be binding or advisory, and if advisory, whether that opinion is admissible in court. If no litigation results within 90 days of the completion of this arbitration, WPAS shall withdraw its access request. Nothing, however, prevents WPAS from renewing its request in the future should that become necessary. In such event that WPAS renews its request, and that request is denied by the State, the ADR process will begin again.

G. Within 120 days of the execution of this agreement, the parties shall select a panel of at least 4 mutually agreeable arbitrators. The parties agree that any one of the selected panel members will arbitrate all disputes related to the Access Agreement. However, the parties will rotate the order of contacting the panel members for each arbitration in a nonstrategical manner.

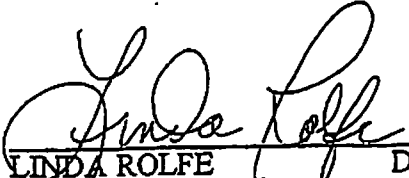
In order to select this panel, within 60 days of the execution of this agreement, the parties will each propose at least 4 arbitrators. The parties will exchange, via fax, their list of proposed arbitrators and the arbitrators' curriculum vitae and any other necessary facts such as cost, etc. If the parties cannot agree upon at least 4 arbitrators from the first exchange of lists, the parties will exchange additional lists of arbitrators until an agreement can be reached. However, a final agreement must be reached no later than 120 days from

the date of the settlement agreement of this case absent written agreement for an extension of a specific amount of time.

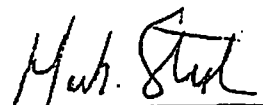
Any party may strike an arbitrator from the list except that a party may not strike an arbitrator from the panel once the arbitration process has been initiated to resolve a dispute. If a party strikes an arbitrator from the panel, that arbitrator will be replaced by another arbitrator using the same arbitrator selection process as described above.

H. The timeframes for dispute resolution shall be as detailed above. Any timeframes not described in this proposal will be those set out in the current relevant access agreements. Any timeframe may be extended by written agreement of the parties.

I. The parties agree they will abide by the timeframes contained in the Access Agreement and this settlement agreement. The parties may mutually agree to extend any timeframe. If a party fails to act or respond within the allotted time, the other party may request appropriate sanctions be imposed as provided by law or civil rule.

 11/17/00

LINDA ROLFE Date
Acting Director
Division of Developmental Disabilities

 1-4-00

MARK STROH Date
Executive Director
Washington Protection & Advocacy System

Exhibit C

David Carlson

From: David Carlson
Sent: Tuesday, January 03, 2012 3:08 PM
To: 'jonb@ATG.WA.GOV'
Subject: P&A Access to Information
Attachments: Complaint (DDD Access).pdf

Importance: High

Jon,

As I mentioned this morning, Disability Rights Washington will be filing a lawsuit to access the names and contact information it requested on December 21st. As a courtesy, I have attached a copy of the Complaint to this email prior to filing it. If Disability Rights Washington does not receive the name and contact information requested by the close of business tomorrow, this complaint, along with a motion for TRO/PI will be filed the following day. I hope your client will come around, as it will save both sides a lot of time and money. If, however, we are forced to file, Disability Rights Washington will seek reimbursement of its fees and costs.

David

David R. Carlson
Associate Director of Legal Advocacy
Disability Rights Washington
315 - 5th Ave South, Suite 850
Seattle, WA 98104
DavidC@dr-wa.org
ph: (206) 324-1521 / 800-562-2702
tty: (206) 957-0728 / 800-905-0209
fax: (206) 957-0729
[Donate 2 DRW](#)

Disability Rights Washington (formerly Washington Protection & Advocacy System) is a private, non-profit organization protecting and advocating for the rights of people with disabilities in Washington since 1977.

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5 UNITED STATES DISTRICT COURT
6 WESTERN DISTRICT OF WASHINGTON
AT TACOMA

7 DISABILITY RIGHTS WASHINGTON,

No. _____

8 Plaintiff,

9 vs.

COMPLAINT

10 LINDA ROLFE, in her official capacity as
11 Director of Division of Developmental
Disabilities, and WASHINGTON DIVISION OF
12 DEVELOPMENTAL DISABILITIES,

13 Defendants.

14 COMES NOW the plaintiff by and through its attorney, and as for its cause of action
15 against the defendants, states and alleges as follows.

16 I. PRELIMINARY STATEMENT

17 1. This civil rights action seeks injunctive and declaratory relief to enjoin
18 Defendants Division of Developmental Disabilities (hereinafter DDD) and its Director, Linda
19 Rolfe, from restricting or interfering with full, complete, and meaningful access of Disability
20 Rights Washington to those individuals with disabilities in the State of Washington, or where
21 applicable, their legal guardians, who are denied or terminated from DDD services based upon
22 their disability. Such access is mandated by the Developmental Disabilities Assistance and Bill
23

1 of Rights Act (hereinafter the DD Act) of 1975, 42 U.S.C. §15041, *et seq.*, and the regulations
2 promulgated thereto and violation of this right to access information violates 42 U.S.C. § 1983.

3 II. JURISDICTION AND VENUE

4 2. This action arises under the laws of the United States. Plaintiff DRW seeks
5 declaratory and injunctive relief pursuant to, the DD Act, 42 U.S.C. §15041, the PAIMI Act, 42
6 U.S.C. § 10801, and the PAIR Act, 29 U.S.C. § 794e, to redress the interference, by Defendant,
7 in DRW's ability to carry out the function of the protection and advocacy system for Washington
8 State by denying DRW the access to individuals with mental illness, and their records that it
9 needs to conduct a full and meaningful investigation in to potential abuse and neglect.

10 3. Jurisdiction in this matter is asserted pursuant to 28 U.S.C. §§ 1331, 2201 for
11 causes of action arising under the Constitution and federal statutory and common laws of the
12 United States.

13 4. The rights which the plaintiff seeks to enforce are guaranteed by Congress
14 through the mandates set forth in the DD Act, 42 U.S.C. §15041, the PAIMI Act, 42 U.S.C. §
15 10801, and the PAIR Act, 29 U.S.C. § 794e. These Acts establish a mandate for DRW to protect
16 and advocate for individuals with developmental, mental, sensory, and physical disabilities who
17 have been abused, neglected, or had their rights otherwise violated.

18 5. This Honorable Court also has authority pursuant to 28 U.S.C. §§ 2201 and 2202
19 to enter declaratory judgments declaring the rights and other legal relations of parties to the
20 action.

21 6. An award of monetary damages is inadequate as plaintiff suffers and will continue
22 to suffer irreparable harm from defendants' actions, inactions, policies, and procedures and the
23 violations complained herein.

7. Venue is proper pursuant to 28 U.S.C. § 1391(b) as all parties reside in the State of Washington and Plaintiff's claim for relief arises within this state. Defendants performed the acts and omissions complained of herein in the State of Washington in this district. This District provides the most convenient forum for the litigation of these issues.

III. PARTIES

Plaintiff

Disability Rights Washington

8. Plaintiff DRW, a nonprofit corporation duly organized under the laws of the State of Washington, is the statewide protection and advocacy system designated by the Governor of the State of Washington to protect and advocate for the legal and civil rights of those citizens of this state who have disabilities, pursuant to the DD Act, 42 U.S.C. § 15041 *et seq.*, the PAIMI Act, 42 U.S.C. § 10801 *et seq.*, and the PAIR Act, 29 U.S.C. § 794e. R.C.W. 71A.10.080(2). DRW maintains its offices at 315 5th Avenue South, Suite 850, Seattle, Washington, 98104.

9. As the duly designated statewide protection and advocacy system for individuals with disabilities in the State of Washington, DRW has the authority and responsibility to pursue legal, administrative, and such other appropriate remedies or relief as may be necessary to protect and advocate for the rights of those persons within the State of Washington who are, or who may be eligible for treatment, services, or habilitation due to their physical and/or mental disabilities pursuant to the DD Act, 42 U.S.C. § 15043, the PAIMI Act, 42 U.S.C. § 108051, and the PAIR Act, 29 U.S.C. § 794e (f).

10. In its capacity as the designated protection and advocacy system for the State of Washington, DRW is entitled to access all persons with disabilities, individually or as a group,

1 receiving services in the State of Washington in order to adequately and meaningfully protect
2 their rights pursuant to federal and state statutes in regard thereto. 42 C.F.R. § 51.2

3 11. DRW has and will continue to suffer irreparable harm as a result of Defendants'
4 actions or inactions absent preliminary and permanent relief.

5 **Defendants**

6 **A. Division of Developmental Disabilities**

7 12. Defendant DDD is the Washington State agency designated to administer or
8 supervise the administration of services to individuals with intellectual disabilities. As such,
9 DDD administers federal and state funds in operating services in a way that ensures compliance
10 with state and federal constitutional and statutory protections for individuals with developmental
11 disabilities.

12 **B. DDD Director Linda Rolfe, in her official capacity**

13 13. Defendant Linda Rolfe is sued in her official capacity as Director of DDD.
14 Defendant Rolfe's administrative office is located in Olympia, Washington.

15 14. Defendant Rolfe, in her official capacity, has at all times relevant herein acted
16 under color of state law and has exercised general responsibility, supervision, and oversight of the
17 policies, practices, and operations of DDD. Defendant Rolfe's responsibilities include overseeing
18 staff responsible for disclosure of information maintained by or otherwise available to DDD.

19 **IV. FACTUAL ALLEGATIONS**

20 15. At all times relevant herein, Disability Rights Washington has been, and is,
21 designated by the Governor of the State of Washington as the protection and advocacy system
22 for those citizens of this state who have mental, developmental, and physical disabilities.
23

1 16. Disability Rights Washington, like each of the protection and advocacy agencies
2 currently operating in the other forty-nine states, the federal protectorates (American Samoa, the
3 Commonwealth of the North Mariana Islands, Guam, Puerto Rico, the Republic of Palau, and the
4 United States Virgin Islands), and the District of Columbia, operates under the mandates of the
5 DD Act, 42 U.S.C. § 15041 *et seq.*, the PAIMI Act, 42 U.S.C. § 10801 *et seq.*, and the PAIR
6 Act, 29 U.S.C. § 794e *et seq.*

7 17. As a result of the extensive congressional hearings preceding each of the aforesaid
8 statutory enactments, Congress found that there had been an extensive history of unlawful
9 discriminatory segregation, extraordinary maltreatment, financial exploitation, neglect, and
10 physical abuse of individuals with disabilities throughout the United States.

11 18. The federal laws that established the protection and advocacy systems were
12 created in direct response to the need for independent advocacy services for individuals with
13 disabilities who were not getting adequate services from state operated programs. *See e.g.*, 42
14 U.S.C. §10501 (11)-(12).

15 19. The Protection and Advocacy Acts (P&A Acts) require that each state, in
16 exchange for receipt of certain federal financial assistance, “effect a system to protect and
17 advocate for the rights of persons” with disabilities and further specify that these systems must
18 have the authority to investigate and pursue legal and other appropriate remedies for those
19 persons. The DD Act, 42 U.S.C. § 15041 *et seq.*, the PAIMI Act, 42 U.S.C. § 10801 *et seq.*, and
20 the PAIR Act, 29 U.S.C. § 794e *et seq.*

21 20. The Washington State legislature provided for such a system with the enactment
22 of R.C.W. 71A.10.080. Specifically, under the provisions of R.C.W. 71A.10.080(1), the
23 designated protection and advocacy agency “shall have the authority to pursue legal,

1 administrative, and other appropriate remedies to protect the rights of the developmentally
2 disabled, and to investigate allegations of abuse and neglect.”

3 21. Disability Rights Washington, in accordance with its congressional mandates,
4 duties, and responsibilities as the designated protection and advocacy agency for Washington,
5 employs attorneys and advocates to provide protection and advocacy services to people in
6 Washington who have mental, developmental, physical, and sensory disabilities.

7 22. Defendants administer Washington’s social service programs designed
8 specifically to meet the need of individuals with developmental disabilities.

9 23. Residents of Washington with developmental disabilities who seek to receive
10 services to meet their needs, must meet DDD’s eligibility criteria in order to receive services
11 administered by DDD.

12 24. Washington statute RCW 71A.10.020 (4) provides that eligibility for DDD
13 services can be established by showing an individual’s disability is caused by any number of
14 conditions, including:

- 15 • intellectual disability,
 - 16 • cerebral palsy,
 - 17 • epilepsy,
 - 18 • autism, or
 - 19 • another neurological condition, or
 - 20 • other condition of an individual found by the secretary to be closely related to
21 an intellectual disability or to require treatment similar to that required for
22 individuals with intellectual disabilities.
- 23

1 25. Disability Rights Washington requested contact information for individuals who
2 have been or will be denied services or terminated from existing services under the final "other
3 conditions" eligibility category.

4 26. The reason for this request is that due to reports Disability Rights Washington has
5 received and information it has obtained it has probable cause to believe the last category listed,
6 "other conditions," is now illusory for a vast number of individuals who were previously eligible.
7 These individuals are now prevented from showing they have a developmental disability because
8 they have a diagnosis which the DDD has disallowed coverage, but which nevertheless meets
9 state and federal statutory requirements. These individuals need the essential services they have
10 either requested or have been receiving for years from DDD. Such categorical exclusions
11 violate federal anti-discrimination laws and Medicaid.

12 27. DDD maintains a list of disabilities which are categorically excluded from being
13 considered under the "other conditions" eligibility category. The list was created by DDD's
14 Other Conditions Determination Committee (hereinafter OCDC).

15 28. The committee's measuring stick for an acceptable "other condition" is one in
16 which the specific diagnosis *by definition* results in intellectual and functional deficits similar to
17 the deficits identified for intellectual disability in each and every person who is diagnosed with
18 the condition in question. The condition is excluded if not every person with the condition has
19 the same level of disability as a person with intellectual disabilities.

20 29. With respect to such conditions in which not each and every person with the
21 condition is affected to the same sever degree, no one may use the diagnosis of that condition to
22 qualify for services, no matter how significant that individual's intellectual and functional
23 deficits may be.

1 30. It is unlawful discrimination for the department to disregard the intellectual and
2 functional deficits of all individuals with traumatic brain injuries, static encephalopathy, Prader-
3 Willi syndrome, fetal alcohol spectrum disorder, and numerous other conditions that typically
4 result in similar disabilities and support needs as those with intellectual disabilities.

5 31. DDD “may not, directly or through contractual or other arrangements, utilize
6 criteria or methods of administration: ¶ (i) That have the effect of subjecting qualified individuals
7 with disabilities to discrimination on the basis of disability; ¶ (ii) [or] That have the purpose or
8 effect of defeating or substantially impairing accomplishment of the objectives of [DDD’s]
9 program with respect to individuals with disabilities. . . .” 28 C.F.R. § 35.130(b)(3) (emphasis
10 added); see also 28 C.F.R. § 41.51(b)(3)(i); 45 C.F.R. § 84.4(b)(4) (Section 504).

11 32. The Other Conditions Determination Committee’s decision to categorically
12 exclude people from consideration on the basis that in order to qualify for services you must
13 have a disability which affects all people to the same significant level without assessing
14 individual need is discriminatory on the basis of disability and impairs, if not completely defeats,
15 DDD’s delivery of services to people who otherwise qualify for DDD programs.

16 33. DDD’s use of the OCDC’s exclusionary list also violates the federal Medicaid
17 Act mandate that participating states provide Early and Periodic Screening Diagnostic and
18 Treatment (EPSDT) services. Under EPSDT, the state must provide services necessary to
19 correct or ameliorate the conditions of Medicaid coverable individuals under the age of 21,
20 regardless of DDD eligibility. 42 U.S.C. § 1396d(r)(5).

21 34. DDD eligibility rules must be met to access all services administered by DDD
22 including but not limited to Washington’s Intermediate Care Facilities (ICFs). RCW 71A.16.020.
23

1 35. DDD eligibility rules must also be met to access Washington's DDD administered
2 Home and Community Bases Services (HCBS) waivers. WAC 388-845-0030.

3 36. Therefore, the OCDC's exclusion of various diagnoses also violates Medicaid
4 rules for ICFs and comparability. 42 U.S.C. § 1396d(d); 42 C.F.R. § 440.150 (a)(2); 42 C.F.R.
5 §440.230.

6 37. Similar to the Washington statute, Medicaid provides that if ICF services are
7 offered by a state, they must be provided to people with "related conditions".

8 38. Medicaid's regulatory guidance does not allow for categorical exclusions based
9 upon disability. 42 U.S.C. § 1396d(d); 42 C.F.R. § 440.150 (a)(2).

10 39. Medicaid requires that sufficient services be provided and that individuals not
11 experience discrimination based on diagnosis. 42 C.F.R. §440.230.

12 40. While Washington has a waiver of comparability in its HCBS waivers, the
13 categorical exclusions of the Other Conditions Determination Committee that have been
14 generated since 2010 go far beyond the scope of the comparability waiver requested in 2008.
15 HCBS Waiver Application version 3.3, Appendix B, a true and correct copy is attached as
16 Exhibit A.

17 41. Finally, the Affordable Care Act requires Maintenance of Effort which precludes
18 states from narrowing the eligibility for their HCBS and ICF programs. See August 5, 2011,
19 State Medicaid Director Letter, a true and correct copy is attached as Exhibit B.

20 42. Disability Rights Washington and others have pointed out to the department that
21 its repeated efforts to restrict access to services violate the Maintenance of Efforts requirement.
22 See November 4, 2009 letter from DRW to Janet Adams, DDD, a true and correct copy is
23

1 attached as Exhibit C; and March 24, 2009 letter from DRW, NJP, and CLS to DSHS rules
2 coordinator, a true and correct copy is attached as Exhibit D.

3 43. Repeated and/or egregious rights violations constitute abuse under the P&A Acts.
4 62 FR 53548, 53551.

5 44. Failure to provide necessary services when legally required to do so constitutes
6 neglect under the P&A Acts. 45 C.F.R. § 1386.19.

7 45. In light of the repeated and egregious potential violations of legal rights by
8 Defendants and the likelihood of extreme irreparable harm experienced by applicants when
9 Defendants withhold necessary services, Disability Rights Washington determined it had
10 probable cause to suspect possible abuse and neglect of individuals with developmental
11 disabilities affected by Defendants' categorical exclusions.

12 46. Disability Rights Washington is the final arbiter of what constitutes probable
13 cause for the purposes of initiating an abuse and neglect investigation. citation

14 47. On December 21, 2011, Disability Rights Washington requested the names and
15 contact of individuals affected by Defendants' categorical exclusion based upon diagnosis.
16 Disability Rights Washington also requested the name and contact information of any guardians
17 for those individuals. This written request for access cited legal authority. The letter included
18 specific support for the release of names and contact information for individuals with whom the
19 protection and advocacy system was not yet in direct contact, but who are affected by abusive or
20 neglectful policies or practices. A true and correct copy is attached as Exhibit E.

21 48. On December 23, 2011, Defendants wrote to indicate they were denying
22 Disability Rights Washington's request. A true and correct copy is attached as Exhibit F. The
23 denial of access provided three rationales:

1 49. DDD asserts that the access agreement between Disability Rights Washington and
2 DDD prevents the department from disclosing the names of individuals who are not current
3 DDD clients.

4 50. DDD asserts that the access authority provided by the DD Acts is limited to
5 individuals with which Disability Rights Washington has a relationship

6 51. DDD asserts that it is not required to provide information about individuals who
7 will be terminated in their next review, because the department believes the likelihood for
8 termination is speculative and thus the request is premature.

9 52. On December 27, 2011, Disability Rights Washington provided a written reply to
10 each of DDD's reasons for not providing the requested names and contact information. A true
11 and correct copy is attached as Exhibit G.

12 53. First, Disability Rights Washington pointed out to DDD that the agreement
13 referenced in DDD's letter is merely intended to operationalize the provisions of the DD Act.
14 The agreement itself acknowledges that it does not limit the authority and obligations generated
15 by the Act in any way. Access Agreement Between WPAS¹ and DDD § I.B.

16 54. Nowhere does federal law limit the duty of disclosure of information to entities
17 currently serving the individual.

18 55. Second, in both its December 21st and 27th letters, Disability Rights Washington
19 explained to DDD that its access authority is not limited to individuals with which it has
20 established a relationship. Disability Rights Washington provided DDD with recent ninth circuit
21

22 _____
23 ¹ Disability Rights Washington was formerly known as Washington Protection and Advocacy System. This
agreement was entered into prior to that name change and therefore the agreement references Plaintiff under its old
acronym, WPAS.

1 case law, directly on point, as well as federal regulatory guidance to support its request. *See*
2 Exhibits E and G, citing *Disability Law Center of Alaska, Inc. v. Anchorage School Dist.*, 581
3 F.3d 936 (9th Cir. 2009)(holding P&A Acts authorize access to otherwise confidential
4 information indentifying people with disabilities and their guardians); *see also* 42 C.F.R. §
5 51.43; 45 C.F.R. § 1386.22(i).

6 56. Defendants failed to provide any support for its narrow reading of the P&A Acts,
7 which they incorrectly assert limit protection and advocacy systems to investigating abuse and
8 neglect of only identified individuals.

9 57. Third, Disability Rights Washington does not consider the harm current DDD
10 clients will sufferer from termination of their necessary Medicaid services to be merely
11 speculative. The unfortunate reality is that due to DDD's categorical exclusion of certain
12 diagnoses under the other conditions criteria, there is nothing speculative about individuals being
13 terminated as a result of their particular diagnosis.

14 58. The department maintains a list of diagnoses that are excluded from consideration
15 for the purposes of qualifying under the other condition category. With respect to future
16 terminations, Disability Rights Washington has requested the names and contact information of
17 only those individuals who previously used one of the now disqualified diagnoses to be found
18 eligible in the past, as these individuals will be terminated if they are ever reassessed.

19 59. Each of these individuals will be terminated at some point.

20 60. Once again, the department provided no legal authority for the limitation it has
21 read into the P&A Acts.

22 61. On December 27th, Disability Rights Washington reiterated its request for the
23 names and contact information of individuals affected by the categorical exclusions.

1 62. Despite the federal statutes which provides Disability Rights Washington access
2 to the requested information within three business days from the initial written request, Disability
3 Rights Washington granted Defendants an additional three days to provide the information.
4 Defendants did not provide the requested names and contact information or any legal authority
5 for its continued denial of access to the information.

6 63. As a result of Defendants' refusal to follow federal law, DRW has been denied
7 access to conduct a full and meaningful investigation and has been unable to fulfill its federal
8 mandate to investigate possible abuse and neglect of individuals with developmental disabilities.

9 64. Defendants have been made aware of Disability Rights Washington's federal
10 authority to obtain a list of names and contact information for a group of individuals and their
11 guardians, when Disability Rights Washington has determined there is probable cause to suspect
12 possible abuse or neglect of that group of individuals.

13 65. Defendants' acts frustrate the congressionally mandated functions and duties of
14 the protection and advocacy system. As described in the foregoing paragraphs, Plaintiff
15 attempted, on multiple occasions, to resolve its access issue with the Defendants. These attempts
16 have proven unsuccessful.

17 66. Plaintiff has suffered and continues to suffer direct and irreparable injury to its
18 statutory interests in investigating abuse and neglect.

19 67. Plaintiff has standing to bring this action on its own behalf, because the refusal of
20 access by defendants constitutes an injury in fact to Plaintiff's legally-protected interests. This
21 injury is concrete, particularized, actual, and imminent. There is a causal relationship between
22 the injury and Defendants' challenged conduct, and a favorable decision by this Court will
23 address the injury.

1 Dated this 3rd day of January, 2011.

2 Respectfully Submitted,

3 DISABILITY RIGHTS WASHINGTON

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5 By:

6 David R. Carlson, WSBA # 35767
7 Attorney for Plaintiff
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Exhibit D

U.S. Department of Health & Human Services

May a covered entity disclose protected health information to a Protection and Advocacy system where the disclosure is required by law?

Answer:

Yes. The Privacy Rule permits a covered entity to disclose protected health information (PHI) without the authorization of the individual to a state-designated Protection and Advocacy (P&A) system to the extent that such disclosure is required by law and the disclosure complies with the requirements of that law. 45 CFR 164.512(a). The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) provides for each state to designate a public or private entity as the Protection and Advocacy system to protect and advocate for the rights of individuals with developmental disabilities, including investigating incidents of abuse or neglect. The P&A designated pursuant to the DD Act is also the Protection and Advocacy system for purposes of the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI Act) and is empowered to protect and advocate for the rights of individuals with mental illness. These statutes and their implementing regulations require that access to records be provided to P&As under certain circumstances. See the DD Act at 42 USCA 15043(a)(2)(I) and (J) and the PAIMI Act at 42 USCA 10805(a)(4), and their implementing regulations at 45 CFR 1386.22 and 42 CFR 51.41, respectively. Thus, a covered entity may disclose PHI as required by the DD and PAIMI Acts to P&As requesting access to such records in carrying out their protection and advocacy functions under these Acts. Similarly, covered entities may disclose PHI to P&As where another federal, state or other law mandates such disclosures, consistent with the requirements in such law. Where disclosures are required by law, the Privacy Rule's minimum necessary standard does not apply, since the law requiring the disclosure will establish the limits on what should be disclosed. Moreover, with respect to required by law disclosures, a covered entity cannot use the Privacy Rule as a reason not to comply with its other legal obligations.

Section 164.512(a)(2) provides that in making a "required by law" disclosure about adult abuse, neglect or domestic violence (section 164.512(c)), for judicial or administrative proceedings (section 164.512(e)), or for law enforcement purposes (section 164.512(f)), covered entities must also comply with any additional privacy requirements in these provisions that apply. However, none of the additional procedural protections in sections 164.512(c), (e) and (f) apply to the type of "required by law" disclosures to P&As under the provisions of the DD and PAIMI Acts discussed here.

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